

The Honorable Marvin L. Abney
Chairman, Committee on Finance
Rhode Island House of Representatives
82 Smith Street, Hearing Room 35
Providence, RI 02903

July 30, 2020

Include House Bill No. 7924, Support Funding for Medicaid Home Care in SFY21 Article 14

Dear Chairman Abney and members of the committee,

My name is Lee Ann. I am a resident of Warwick and a constituent of Representative Joseph M. McNamara and Senate Majority Leader Michael J. McCaffrey. My son Zachary and I testified before this committee in 2016 as well as in 2018 and 2019. I am back now to ask you to consider a reimbursement rate increase for high acuity PDN nursing in Rhode Island. The current home care situation scares myself and my family.

My son is 20 years old he has Duchenne Muscular Dystrophy which is a progressive neuromuscular disease effecting every muscle in his body. 15 years ago when he was diagnosed the average life expectancy was late teens. Medical advancements, and more aggressive treatment of respiratory, cardiac complications and a more proactive and aggressive approach to care has advanced the average life expectancy into mid-twenties early 30. His disease is progressing and in February he was had an extensive hospitalization resulting in surgery to place a tracheostomy so that he is able to breathe. He is also on a ventilator to control his breathing. When the tracheosotmy was placed he also had a Peg Tube placed so that Zachary can now be fed safely. After 87 days and two hospitals he returned home on 5/1/2019.

Nurses who can care for Zach at home are being paid more in a hospital... why would they leave?

I work full time, I have three other children 14, 14 and 4, my husband works full time, my parents 65 and 70 help keep an eye on my children in the time between my husband leaving for work and my coming home. My husband and I have not been on vacation alone in the last 15 years. There is no prospect of being able to take even my three other children on a vacation because my husband and I are the only family members trained in his care when he does not have a nurse in the home. We have renovated my home to keep my son at home. As his disease progresses, and we have need skilled services like nursing to continue to keep Zachary at home with his family where he belongs.

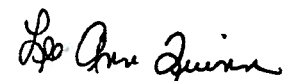
I am a nurse and I work in the home care industry. I have a unique outlook on the current crisis facing home care in Rhode Island - not just as a client, but also as a nurse. **I am looking into a very uncertain future for my son and my family.**

The level of care provided in my home is similar to what the nurses in the RICU were providing and is similar to the same level of care provided in ICU settings in our hospitals. The one exception is that the nurses in my home do it without the support of respiratory therapy, docotors at the bedside, and other licensed and support staff available to help. My nurses in fact do a number of tasks that the RICU nurses that were so recently caring for my son are not allowed to do because the respiratory therapist provides that care in the hospital not the nurse. My nurses must have the training and the experence to provide continuous care and handle ANY emergency that happens. We are currently expecting the nurses who are caring for some of our most vulnerable adults and children at home to provide care at a rate where they are making less money than their counterparts in a different setting. Nurses who can care for Zach at home are being paid \$35-45/hr in a hospital... why would they leave? In home care, after the recent rate increase, nurses will just start to be paid around \$30/hour.

My family needs home care nursing to be a viable option for my son to remain at home. My son, and my family started on this journey 16 years ago and along the way we have fought for services, school, and equipment to name a few. We are willing to fight for Zachary to remain at home with his family as his care becomes more complicated. As a taxpayer and a mom investing in nursing and home care now is a good investment for Rhode Island. Home care is cheaper than paying for 24 hour care in a facility and it maintains a quality of life that he would not have in a facility. He is happy at home he is part of the flow of our home and can play games with his little sister, talk and play video games with his older sisters, watch movies as a family all the things we struggled to be able to do while he was in a facility. The ability to attract quality nurses to home care keeps medically fragile children and adults out of hospitals, keeps families together and allows parents to work and provides a quality of life that does result in improved health and outcomes for everyone.

Please help to ensure that home care remains an option for Zachary others like him who belong at home with their families. If you have further questions for myself or for Zachary, we would be pleased to answer them.

Respectfully,



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